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Health Care Needs of Children with Tourette Syndrome

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Abstract

In order to document the impact of Tourette Syndrome on the health care needs of children, and access to health care among youth with Tourette Syndrome, parent-reported data from the 2007–2008 National Survey of Children's Health were analyzed. Children with Tourette Syndrome had more co-occurring mental disorders than children with asthma or children without Tourette Syndrome or asthma, and had health care needs that were equal to or greater than children with asthma (no Tourette Syndrome) or children with neither asthma nor Tourette Syndrome. Health care needs were greatest among children with Tourette Syndrome and co-occuring mental disorders, and these children were least likely to receive effective care coordination. Addressing co-occurring conditions may improve the health and well-being of children with Tourette Syndrome. Strategies such as integration of behavioral health and primary care may be needed to improve care coordination.

Keywords

Tourette Syndrome; mental disorders; health care; care coordination; behavioral health

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Author contribution: Rebecca Bitsko lead the writing and statistical analyses. Melissa Danielson assisted with analyses including replication of final results, Michael King provided expertise on asthma, and wrote sections specific to asthma. Susanna Visser provided statistical support and assisted with study design. Lawrence Scahill provided expertise on Tourette Syndrome, including treatment. Ruth Perou contributed to the study design and policy implications. All co-authors reviewed and commented on drafts of the manuscript.

Introduction

Tourette Syndrome is a neurological condition defined by the presence of persistent motor and vocal tics.[1] Community-based prevalence estimates range from 3–8 per 1000 children,[2–7] and a recent estimate from a nationally representative population of children living in the United States of America found that 3 per 1000 children had a Tourette Syndrome diagnosis.[8] Symptoms of Tourette Syndrome range from mild to severe, with most cases showing mild or moderate symptoms.[8–11] In community and clinically ascertained samples, over half of children with Tourette Syndrome have a co-occurring mental, emotional, or behavioral condition[12] most commonly attention-deficit/hyperactivity disorder and obsessive-compulsive disorder.[4, 8, 13–15] These co-occurring conditions often contribute to the adverse impact of Tourette Syndrome on educational outcomes, family stress, social relationships and health care needs.[16–19, 20]

In the absence of co-existing mental, emotional or behavioral conditions, children with mild tics may not require additional treatment beyond health education for the child and family.[21] However, when tics are moderate or greater in severity, available treatments include medication and systematic habit reversal training.[21–24] Medications rarely eliminate all tics and may be associated with adverse effects that limit their use to individuals with prominent symptoms that interfere with daily life.[23] The presence of co-occurring mental, emotional or behavioral conditions, or educational difficulties complicates the treatment of children with Tourette Syndrome as these children often require additional medical and educational services.[25]

Although the presence and impact of co-occurring conditions among children with Tourette Syndrome are well-documented,[26–28] few studies have examined health care needs and health service use among these children. For example, children and adults with Tourette Syndrome have lower healthrelated quality of life as evidenced by lower scores on measures of psychological health and adaptive function; this lower quality of life appears to be associated with tic severity and co-occurring psychiatric conditions.[26–28] Tourette Syndrome may also be associated with lower indices of physical health.[28] Likewise, in a recent study using data from Medicaid and private insurance claims of children aged 4 to 18 years with Tourette Syndrome and other tic disorders, Olfson and colleagues reported that 50–75% of youth with Tourette Syndrome had co-occurring mental disorders.[15] Youth with Tourette Syndrome used more mental health services and psychotropic medications than youth with other tic disorders (e.g., chronic motor or vocal tic disorder and transient tic disorder) and youth without any tic disorder.[15] Among children with Tourette Syndrome, 73% of publicly insured children and 85% of privately insured children had at least one prescription for a psychotropic medication during the one year study period.[15] Thus, although some mental health and psychological needs of children with Tourette Syndrome have been reported, details on other health and health care needs are limited.

We analyzed data from the National Survey of Children's Health to document the health care needs among a nationally representative sample of children living in the United States of America with and without Tourette Syndrome.[29] In order to illustrate the needs of children with Tourette Syndrome relative to another chronic condition, children with asthma

were chosen as a clinical control group. Asthma is a relatively common chronic condition, affecting 9.1% of children living in the United States of America in 2007,[30] and has been used as a comparison group in previous studies of health care needs.[31–34] Specifically, asthma has been used as a comparison group for attention-deficit/hyperactivity disorder in studies examining whether children had a medical home, unmet health care needs, and measures of health-related quality of life, including behavior, mental health, physical functioning, and self-esteem.[31, 33, 34] Similar to Tourette Syndrome, asthma varies in severity across individuals, has a fluctuating course of symptoms over time, requires ongoing health care management,[35, 36] and is often associated with co-occurring mental disorders, which may complicate treatment beyond routine care.[37–39] Specifically, children with asthma and co-occurring mental disorders often require more complex medication regimens, as well as more intensive education about disease management and environmental precautions to prevent worsening of symptoms.[37, 40, 41]

This study tested four hypotheses: 1) children with Tourette Syndrome would have greater overall health care needs, and mental health care needs in particular, compared to children in comparison groups (children without Tourette Syndrome or asthma and children with asthma but no Tourette Syndrome); 2) children with Tourette Syndrome and one or more co-occurring mental disorders would have greater health care needs and more problems with care coordination compared to children with Tourette Syndrome without a co-occurring mental disorder; 3) children with a current diagnosis of Tourette Syndrome would have greater health care needs than those with a previous diagnosis of Tourette Syndrome; and 4) more severe Tourette Syndrome would be associated with more health care needs.

Methods

The 2007–2008 National Survey of Children's Health is a nationally representative, population-based survey of parents of children under the age of 18 living in the United States of America (including all 50 states and the District of Columbia); data are publically available.[29] Parents reported on their child's general health, presence of specific health conditions, their experiences with the health care system, as well as questions about activities, family demographics, and neighborhood characteristics. The cooperation rate among households identified as having children was 66%.[29] The National Center on Health Statistics ethical review board and the NORC Institutional Review Board approved all study procedures and modifications. The Federal Office of Management and Budget control number for this collection of information was 0920-0406.[29]

The survey questions of primary interest included those about family demographics, specific health conditions, and questions related to health, including a 5-part screener to identify children with special health care needs[42] (see Table 1). Children were considered to have a mental disorder[1] if their parent reported they had attention-deficit/hyperactivity disorder, a behavioral or conduct problem, depression, anxiety problems or an autism spectrum disorder (see Table 1). The presence of an externalizing disorder was defined by parent report of attention-deficit/hyperactivity disorder or other behavioral or conduct problem, while the presence of an internalizing conditions included depression or anxiety problems; Table 1). Because of the high rate of co-occurrence among these conditions, these groups were not

mutually exclusive. A series of questions assessed whether the parent thought the child received effective care coordination, family-centered care and whether the child had a medical home.[43–46]

Because Tourette Syndrome is rarely diagnosed in younger children, analyses of health care needs were limited to children aged 6–17 years (un-weighted n = 64,034).[1, 23, 47] First, children with current Tourette Syndrome (including those with asthma) were compared to children with current asthma but no Tourette Syndrome (asthma), and to children without previous or current Tourette Syndrome or asthma (general population; children with previous but not current Tourette Syndrome or asthma were excluded from these analyses; see Figure 1a). Second, analyses compared sub-groups of children with Tourette Syndrome and children without Tourette Syndrome (see Figure 1b): (1) children with current Tourette Syndrome to children with previous Tourette Syndrome, and each of these groups to children without Tourette Syndrome (Never Tourette Syndrome); (2) children with Tourette Syndrome (previous or current) and a co-occurring mental disorder (Tourette Syndrome +mental disorder) and children with Tourette Syndrome without a co-occurring mental disorder (Tourette Syndrome-only) and each of these groups to children without Tourette Syndrome (Never Tourette Syndrome); and (4) among those with current Tourette Syndrome, children with moderate or severe Tourette Syndrome to children with mild Tourette Syndrome.

The group of children with current Tourette Syndrome included children with current asthma in order to capture the health care needs of all children with Tourette Syndrome; supplementary analyses included a group of children with Tourette Syndrome but not asthma. We used chi-square tests and multivariate logistic regression to test for group differences and associations between variables of interest. We used SAS-callable SUDAAN (Version 10.0.1, RTI International, NC) to account for the complex sampling design of the National Survey of Children's Health, and sample weights to produce estimates that were generalizable to the population of children 6–17 years of age living in the United States of America. We calculated weighted percent estimates, prevalence ratios, and 95% confidence intervals (CI) for all estimates and prevalence ratios. All prevalence ratios (except for analyses comparing severity because sample size was too small) were adjusted for child sex, age (6–11 vs. 12–17 years), race (white vs. other), and ethnicity (Hispanic vs. not). Because asthma was associated with poverty, the analyses comparing the Tourette Syndrome and asthma groups to the general population (Table 2) were also adjusted for poverty (less than or equal to 200% of federal poverty level vs. greater than 200% of federal poverty level). Single imputed values for the poverty variables were used in the models for the approximately 8% of respondents who did not report family income.[29] We conducted t-tests to compare the mean number of co-occurring conditions between groups. We calculated relative standard errors (standard error/prevalence estimate×100%) for each estimate; estimates with a relative standard error > 30% are noted, and estimates with a relative standard error > 50% are suppressed.

Results

Demographics and co-occurring conditions

As previously reported, the prevalence of current Tourette Syndrome among children 6–17 years of age living in the United States of America was 0.19% (CI: 0.13, 0.27, n = 147), representing approximately 92,000 children (see Table 2).[8] Among those with current Tourette Syndrome, 21.5% (CI: 10.4–39.3, n = 22) also had current asthma (included in Tourette Syndrome group), while the prevalence of asthma among children without current Tourette Syndrome was 10.3% (CI: 9.7–10.9, n=6,328; asthma group).

In agreement with a previous report, a higher proportion of children with current Tourette Syndrome were male and non-Hispanic compared to the general population[8]. There was no difference in age, race, and household income between children with current Tourette Syndrome and the general population. Also consistent with previous findings, a higher proportion of children in the asthma group were male, non-white, and living in poverty compared to the general population[48]. Compared to children in the asthma group, children with current Tourette Syndrome were more likely to be male (prevalence ratio = 1.4, CI: 1.2, 1.6), and white (prevalence ratio = 1.4, CI: 1.2, 1.6); there were no significant differences between children with current Tourette Syndrome and children in the asthma group for age, ethnicity or poverty status.

Children with current Tourette Syndrome were more than six times as likely as those in the general population or the asthma group to have a concurrent mental disorder, or externalizing condition, and over 12 times as likely to have a concurrent internalizing condition or autism spectrum disorder (Table 2). Children in the asthma group were at least twice as likely as children in the general population to have a concurrent mental disorder, externalizing or internalizing condition, but there was no difference in the rate of autism spectrum disorder. Compared to children in the asthma group, children with current Tourette Syndrome were significantly more likely to have a concurrent mental disorder (adjusted prevalence ratio = 3.0, CI: 2.3, 3.7), internalizing problem (adjusted prevalence ratio = 4.7, CI: 3.2, 6.9), externalizing problem (adjusted prevalence ratio = 3.1, CI: 2.3, 4.3), or autism spectrum disorder (adjusted prevalence ratio = 11.3, CI: 5.2, 24.4). Children with current Tourette Syndrome also had a significantly ($p<0.001$) greater number of concurrent mental disorders (mean 1.6, CI: 1.2, 2.1), than the asthma group (mean 0.4, CI: 0.3–0.4) or the general population (mean 0.17, CI: 0.16, 0.18). The difference in the number of concurrent mental disorders between children with current Tourette Syndrome and those with current asthma was also significant ($p<0.001$).

Health and health care needs among children with Tourette Syndrome and children with asthma

Compared to children in the general population, parents of children with current Tourette Syndrome or current asthma were more likely to report their child's overall health as "fair or poor", and more likely to report greater health care needs on nearly every measure (Table 3). On indices of health care access, children with current Tourette Syndrome were less likely than children in the general population to receive effective care coordination. Whether or not

the child had a medical home approached statistical significance (38.9% of children with Tourette Syndrome vs. 55% of children in the general population, adjusted prevalence ratio = 0.7; 95% CI: 0.5,1.0). Children with current asthma did not differ from children in the general population on measures of health care access (Table 3).

Compared to parents of children with asthma, parents of children with current Tourette Syndrome were more likely to endorse limitations in their child's "ability to do things most children of the same age can do" (adjusted prevalence ratio 1.9, CI: 1.2, 2.9), report the presence of an emotional, developmental, or behavioral problem in need of treatment (adjusted prevalence ratio 3.3, CI: 2.5, 4.4), and to report their child needed or used more medical care, mental health, or educational services (adjusted prevalence ratio 2.0, CI: 1.4, 2.8), needed or received special therapy (adjusted prevalence ratio 2.2, CI: 1.2, 3.9), received treatment or counseling from a mental health professional (adjusted prevalence ratio 2.3, CI: 1.5, 3.6), or had taken any medication because of difficulties with his/her emotions, concentration or behavior, including for attention-deficit/hyperactivity disorder (adjusted prevalence ratio 3.7, CI: 2.7, 5.1), in the previous year. In contrast, the need for prescription medicine (in general) approached statistical significance (Tourette Syndrome vs. general population adjusted prevalence ratio 0.7; 95%: CI: 0.5, 1.0).

Supplementary analyses exploring the health care needs of children with current Tourette Syndrome but not asthma generally agreed with the findings presented on all children with current Tourette Syndrome. Although the magnitude of the differences between children with current Tourette Syndrome without asthma compared to children in the general population were lower than that observed with the full Tourette Syndrome group, the risk ratios were significant. The only exception was care coordination, which was no longer significant (adjusted prevalence ratio = 0.7, CI: 0.4, 1.2).

Contrasts between children with current Tourette Syndrome without asthma and children with asthma but not Tourette Syndrome showed similar findings (to Tourette Syndrome plus asthma group). Whether the "child is limited or prevented in any way in his/her ability to do the things most children of the same age can do" was no longer statistically stable (relative standard error = 35.3%) and whether a "child needs or gets special therapy such as physical, occupational or speech therapy" was no longer significant (adjusted prevalence ratio = 1.8, CI: 1.04, 3.2).

Health care needs of children with a previous versus current diagnosis of Tourette Syndrome

Children with previous Tourette Syndrome (but not current diagnosis) and those with current Tourette Syndrome had a greater number of health care needs compared to children without Tourette Syndrome ("never Tourette Syndrome"). Children with current Tourette Syndrome were significantly more likely to have seen a specialist other than a mental health professional in the past year, compared to the never Tourette Syndrome group; this was not significant for the previous Tourette Syndrome group. In addition, those with current Tourette Syndrome were less likely to receive care coordination compared to the never Tourette Syndrome group; this difference was not significant between the group with previous Tourette Syndrome and children without Tourette Syndrome.

Severity of Tourette Syndrome

When comparing children with moderate or severe Tourette Syndrome to those with mild Tourette Syndrome, health care needs were generally greater for those with moderate or severe Tourette Syndrome. According to unadjusted prevalence ratios, those with moderate or severe Tourette Syndrome were more likely to need or use more medical care, mental health or educational services (prevalence ratio 1.8, CI: 1.2, 2.8), to need special therapy (prevalence ratio 5.3, CI: 2.4, 12.1), and to meet criteria for children with special health care needs (prevalence ratio 1.6, CI: 1.1, 2.4) than those whose parents reported mild Tourette Syndrome. The estimate for needing special therapy had a relative standard error of 37%, and thus, should be interpreted with caution.

Co-occurring mental disorders

Children with Tourette Syndrome-only and Tourette Syndrome with a co-occurring mental disorder (Tourette Syndrome+mental disorder) each had significantly more health care needs than children in the never Tourette Syndrome group. Children with Tourette Syndrome-only were more than twice as likely to need medicine prescribed by a doctor, to use more medical care, mental health, or educational services, and to meet criteria for children with special health care needs than children in the never Tourette Syndrome group (Table 4). The strength of this association was higher in the Tourette Syndrome+mental disorder group for every indicator of health and health care need (see Table 4).

Discussion

Children with Tourette Syndrome have health care needs similar to or greater than those of children with asthma, and greater than those of children in the general population. Although some children may outgrow tic symptoms and no longer meet criteria for Tourette Syndrome by young adulthood,[1, 47] these children may still encounter substantial health care needs related to co-occurring mental, emotional and behavioral disorders. Indeed, parents of children with a history of Tourette Syndrome (previous Tourette Syndrome), but not current Tourette Syndrome, reported more health care needs than parents of children who never had Tourette Syndrome. Moreover, these reports were similar to parents of children with current Tourette Syndrome. Children with moderate or severe Tourette Syndrome had more health care needs than those with mild Tourette Syndrome.

In agreement with previous studies,[8, 15] there was a high prevalence of co-occurring mental disorders among children with Tourette Syndrome. Children with Tourette Syndrome and a mental disorder consistently had greater health care needs; this difference was true for both co-occurring internalizing and externalizing conditions. This agrees with a previous study showing an increased need for mental health services among children with tic disorders and attention-deficit/hyperactivity disorder, but not tic disorders alone.[7] This is also consistent with findings from a previous study showing that cooccurring mood disorders were strongly associated with psychiatric hospitalization among children with Tourette Syndrome, even more so than tic severity.[20] Parents of children with Tourette Syndrome were less likely to report that they received effective care coordination compared to the general population; this difference remained significant for the Tourette Syndrome+mental disorder group, but not

the Tourette Syndrome-only group. Thus, the presence of co-occurring conditions may increase the care coordination challenges facing families of children with Tourette Syndrome.

The issue of co-occurring conditions complicating health care needs is not specific to Tourette Syndrome. Youth with other chronic conditions, including epilepsy, asthma and emotional, behavioral or developmental conditions are also at risk for co-occurring mental, emotional and behavioralconditions.[38, 39, 49, 50] As shown here and previously, children with asthma also have elevated rates of co-occurring mental disorders that may affect service needs.[37–39] Although children with asthma had a higher prevalence of co-occurring conditions than children in the general population, the prevalence was significantly lower than among children with current Tourette Syndrome. Most of the differences in health care needs between children with current Tourette Syndrome and children in the asthma group were associated with mental health care needs.

Complicating quality care coordination further, families may face challenges in access. Knowledge gaps among providers, and a shortage of experts in treating children with Tourette Syndrome, especially children with co-occurring mental, emotional and behavioral conditions, may partially account for these challenges.[51–53] One specific gap identified in a study of physicians and psychologists was knowledge about behavior therapy; slightly more than a third of the providers knew about habit reversal training for tics, but fewer than 10% knew how to implement it.[51] Challenges in the dissemination of information about behavioral treatments for tics and a shortage of providers trained in child and adolescent mental health may also contribute to this gap.[52–54] Chronic care models of healthcare delivery that rely on multidisciplinary teams and outreach may improve access to care for people with multiple chronic mental, emotional or behavioral conditions.[55] Dissemination of evidence-based information about Tourette Syndrome, co-occurring mental, emotional and behavioral conditions, and evidence-based treatment (including behavior therapy) could further enhance access to care.

These findings should be interpreted within the context of the study survey and its associated limitations. Although the study included a large national sample of children with Tourette Syndrome, it relied on parent report of diagnosis and therefore may have been influenced by ascertainment bias. Specifically, children with more mild symptoms who never received a diagnosis of Tourette Syndrome would not have been included in the Tourette Syndrome sample. Also, despite the large overall sample, the size of the Tourette Syndrome subgroups (e.g. Tourette Syndrome-only and severity) was relatively small and some results were not statistically reliable (i.e., had high relative standard errors) and should be interpreted with caution.

The findings reported here demonstrate significant health care needs and challenges with care coordination for children with Tourette Syndrome, including those with and without co-occurring mental, emotional and behavioral conditions. Based on evidence in children with other special health care needs, connecting to a medical home may be one promising approach to helping children with Tourette Syndrome achieve improved care coordination and the better overall health outcomes that can come with it.[56, 57] Recent health policies and

guidelines may also help address some of the challenges faced by children with Tourette Syndrome and co-occurring conditions, including the Mental Health Parity and Addiction Equity Act (P.L. No. 110–343)[58] and the Patient Protection and Affordable Care Act (P.L. No. 111–148), each of which promote better integration of primary and mental health services.[45, 59, 60] Future analyses of national surveys will be helpful in tracking the impact of public health policies and programs on health care access and care coordination for children with Tourette Syndrome and co-occurring mental, emotional and behavioral conditions.

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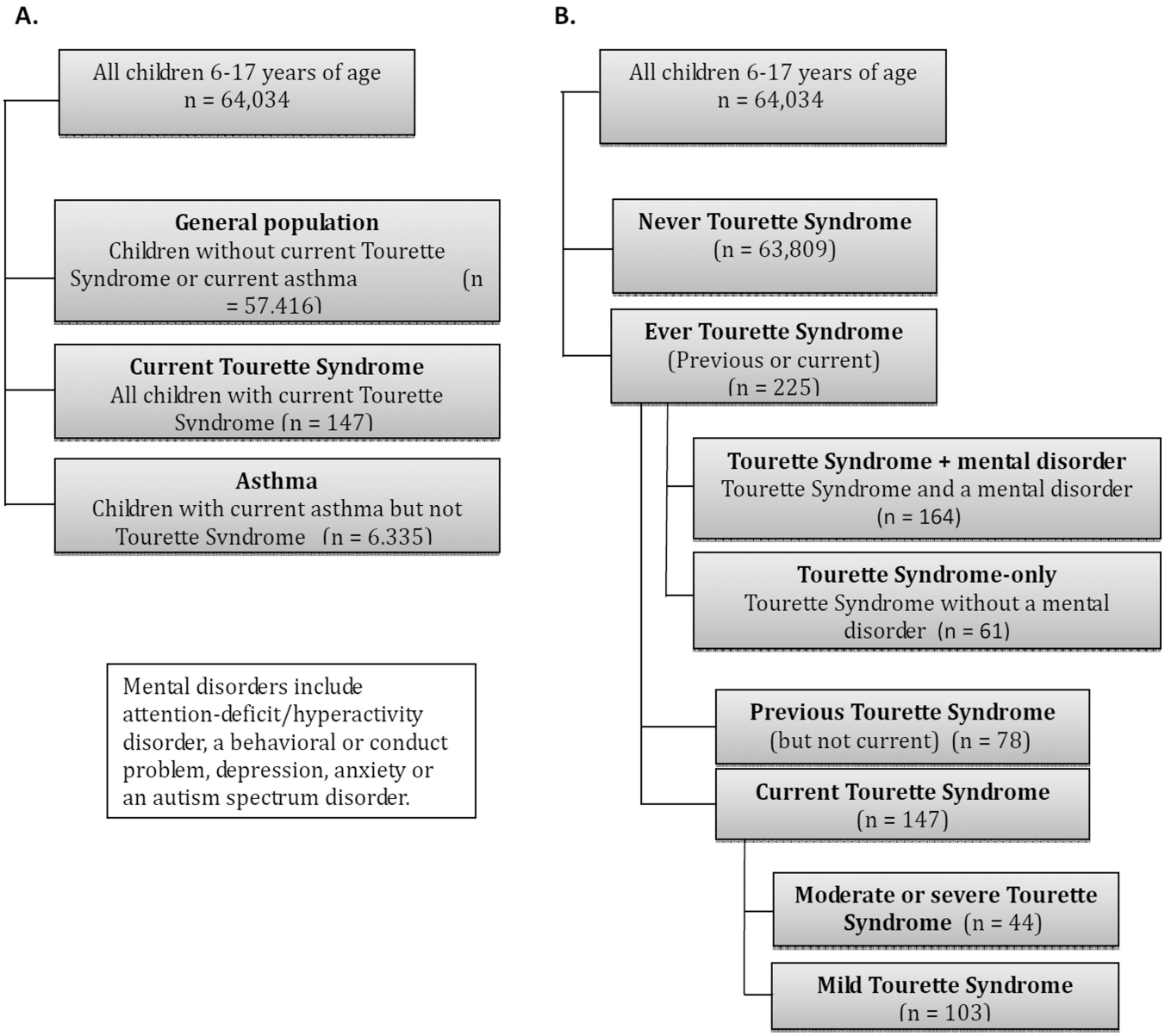

Figure 1.

Analytic groups (with un-weighted sample sizes) for health care needs among children with Tourette Syndrome, 2007 National Survey of Children's Health. A. Groups comparing children with current Tourette Syndrome, current asthma without Tourette Syndrome, and children without Tourette Syndrome or asthma. B. Analyses of sub-groups of children with Tourette Syndrome compared with children without Tourette Syndrome, or to each other.

Table 1

Questions from the 2007 National Survey of Children's Health used for analyses of health care needs among children with Tourette Syndrome

NSCH Question	Other Information	Variables
Does (the child) currently have (specified condition). Conditions included for this study: Tourette Syndrome; asthma; attention-deficit disorder or attention deficit hyperactivity disorder; depression; anxiety problems; behavioral or conduct problems such as oppositional defiant disorder or conduct disorder; autism, Asperger's disorder, pervasive developmental disorder, or other autism spectrum disorder.	Conditions: This question was asked of parents who answered yes at least once to the question "Has a doctor or other health care provider ever told you that (the child) had (specified condition)?"	Tourette syndrome; asthma; any mental disorder (any condition listed in the first column except Tourette Syndrome or asthma); externalizing conditions (attention-deficit/hyperactivity disorder or a behavioral disorder); internalizing conditions (anxiety, depression); autism spectrum disorder
1. Would you describe his/her (specified condition) as mild, moderate or severe	This questions was asked of parents who answered yes to question 2 (child currently has a condition; asked for each current condition)	Severity; mild versus moderate or severe
2. How would you describe (the child's) health? Would you say his/her health is excellent, very good, good, fair, or poor?	Dichotomized to fair or poor versus good, very good or excellent.	Overall health fair or poor
3. Child with a special health care need Criteria: - Does the child currently need or use medicine prescribed by a doctor, other than vitamins? - Does (the child) need or use more medical care, mental health or educational services than is usual for most children of the same age? - Is (the child) limited or prevented in any way in his/her ability to do the things most children of the same age can do? - Does (the child) need or get special therapy, such as physical, occupational, or speech therapy? - Does (the child) have any kind of emotional, developmental or behavioral problem for which he/she needs treatment or counseling?	Each of these questions was included as an outcome. Additional questions about whether these needs were associated with any medical, behavioral, or other health condition, and whether this condition had lasted or was expected to last 12 months or longer were used to determine the children with special health care needs status.[42]	- Needs or uses medicine prescribed by a doctor - Needs or uses more medical care, mental health or educational services - Limited or prevented in ability to do things - Needs or gets special therapy - Has an emotional, developmental or behavioral problem for which he/she needs counseling - Meets criteria for children with special health care needs
4. Health Care Needs: - During the past 12 months, has (the child) received any treatment or counseling from a mental health professional - During the past 12 months, did (the child) see a specialist other than a mental health professional? - During the past 12 months, has (the child) taken any medication because of difficulties with (his/her) emotions, concentration, or behavior? - Is (the child) currently taking medication for attention-deficit disorder or attention-deficit/hyperactivity disorder?	The final two questions about whether the child took medication for emotions, concentration or behavior and whether the child was taking medication for attention-deficit/ hyperactivity disorder were combined in order to have one outcome for taking a medication for mental health or behavioral problems. The question about attention-deficit/hyperactivity disorder medication was only asked of parents who answered yes that there child currently had attention-deficit disorder or attention-deficit/ hyperactivity disorder.	- Received treatment or counseling from a mental health professional - Taken medication for difficulties with emotions, concentration or behavior, including attention-deficit/ hyperactivity disorder - Seen a specialist (other than mental health)

Table 2

Demographics and prevalence of parent-reported co-occurring mental disorders among children with current Tourette Syndrome, children with current asthma without Tourette Syndrome, and children without Tourette Syndrome or asthma

		All Current Tourette Syndrome (n = 147)		Current Asthma without Tourette Syndrome (n = 6,335)		General Population (No Tourette Syndrome or asthma) (n = 57,416)	
		% (95% CI) ††	aPR†† (95% CI)	% (95% CI)	aPR (95% CI)	% (95% CI)	aPR (95% CI)
Sex	Male	78.9 (65.9, 87.8)	1.6 (1.4, 1.8)	57.5(54.6, 60.4)	1.1 (1.1, 1.2)	50.4 (49.3, 51.4)	Referent
	Female	21.1 (12.2, 34.1)		42.5 (39.7, 45.4)		49.6 (48.6, 50.7)	
Age	6–11 years	37.2 (22.8, 54.4)		49.0 (46.0, 52.0)		48.5 (47.5, 49.6)	
	12–17 years	62.8 (45.6, 77.2)	1.2 (0.9, 1.6)	51.0 (48.0, 54.0)	1.0 (0.9, 1.1)	51.5 (50.4, 52.5)	Referent
Race	White	82.0 (62.9, 92.4)	1.1 (0.9, 1.3)	60.7 (57.7, 63.7)	0.8 (0.8, 0.9)	73.6 (72.6, 74.5)	Referent
	non-White	18.0 (7.6, 37.1)*		39.3 (36.3, 42.3)		26.4 (25.5, 27.4)	
Ethnicity	Not-Hispanic	90.8 (81.8, 95.6)	1.1 (1.1, 1.2)	84.3 (81.3, 86.8)	1.1 (1.0, 1.1)	80.4 (79.3, 81.4)	Referent
	Hispanic	9.2 (4.4, 18.2)*		15.8 (13.2, 18.7)		19.6 (18.6, 20.7)	
Household Income	≤200% of federal poverty level	42.7 (24.3, 63.4)	1.2 (0.7, 1.9)	43.9 (40.8, 47.1)	1.2 (1.1, 1.3)	36.3 (35.3, 37.4)	Referent
	>200% of federal poverty level	57.3 (36.6, 75.7)		56.1 (52.9, 59.2)		63.7 (62.6, 64.7)	
Co-occurring mental disorders	Any mental disorder††	68.8 (53.9, 80.6)	6.3 (5.1, 7.7)	23.4 (20.7, 26.2)	2.1 (1.9, 2.4)	11.0 (10.4, 11.6)	Referent
	Externalizing††	58.6 (41.5, 73.8)	6.7 (5.0, 9.0)	18.6 (16.2, 21.4)	2.1 (1.8, 2.5)	8.7 (8.2, 9.3)	Referent
	Internalizing††	50.5 (33.6, 67.3)	12.8 (8.9, 18.3)	10.8 (9.0, 12.9)	2.7 (2.2, 3.4)	4.0 (3.6, 4.4)	Referent
	Autism Spectrum Disorder ††	13.4 (7.0, 24.2)*	12.1 (6.2, 23.3)	1.2 (0.8, 1.9)	1.1 (0.7, 1.7)	1.1 (0.9, 1.4)†	Referent

† This estimate agrees with the National Survey of Children's Health chartbook[50] and a previous report from the National Survey of Children's Health.[61]

†† Abbreviations: CI = confidence interval; aPR = adjusted prevalence ratio; Externalizing disorders = attention-deficit/hyperactivity disorder or attention-deficit disorder, and behavioral problems including oppositional defiant disorder or conduct disorder; internalizing disorders = depression and anxiety problems.

* Relative standard error > 30%. For non-white Tourette Syndrome, relative standard error = 41%; Hispanic Tourette Syndrome relative standard error = 37%; relative standard error = 35% for Tourette Syndrome Autism Spectrum Disorder estimate and relative standard error = 36% for Tourette Syndrome Autism Spectrum Disorder aPR.

Table 3

Indicators of health, health care needs and health care access among all children with current Tourette Syndrome, children with current asthma without Tourette Syndrome, and children without Tourette Syndrome or asthma

	All Current Tourette Syndrome (n = 147)		Current Asthma without Tourette Syndrome (n = 6,335)		General Population (No Tourette Syndrome or asthma) (n = 57,416)	
	% (95% CI) †	aPR† (95% CI) %	(95% CI)	aPR (95% CI)	% (95% CI)	aPR
General Health Overall Health Fair or Poor	13.9 (7.2, 25.1)	4.6 (2.0, 10.2)	10.7 (8.9, 12.9)	4.0 (3.1, 5.1)	3.2 (2.7, 3.7)	Referent
Special Health Care Needs						
- Needs or uses medicine prescribed by a doctor	52.4 (34.7, 69.5)	3.0 (2.0, 4.4)	77.5 (74.9, 80.0)	4.5 (4.2, 4.7)	17.1 (16.3–17.9)	Referent
- Needs or uses more medical care, mental health, or educational services	63.6 (43.1, 80.1)	5.3 (3.7, 7.7)	32.4 (29.6, 35.3)	2.7 (2.4, 3.0)	11.6 (11.0, 12.3)	Referent
- Limited or prevented in ability to do things	41.2 (23.9, 61.1)	6.7 (4.3, 10.4)	20.0 (17.7, 22.5)	3.4 (2.9, 3.9)	5.6 (5.1, 6.1)	Referent
- Needs or gets special therapy	25.0 (13.3, 42.1)	3.4 (2.0, 6.0)	11.5 (9.7, 13.6)	1.6 (1.3, 1.9)	6.9 (6.4, 7.5)	Referent
- Has an emotional, developmental or behavioral problem for which he/she needs counseling	56.0 (39.5, 71.3)	6.3 (4.8, 8.2)	16.9 (14.9, 19.2)	1.9 (1.6, 2.2)	8.2 (7.7, 8.8)	Referent
- Meets Criteria for children with special health care needs†	70.0 (46.8, 86.1)	3.9 (2.7, 5.6)	69.9 (67.0, 72.7)	4.0 (3.8, 4.2)	17.4 (16.6, 18.1)	Referent
Health Care Needs						
- Received treatment or counseling from a mental health professional	42.6 (25.9, 61.3)	4.1 (2.6, 6.4)	17.6 (15.3, 20.1)	1.8 (1.5, 2.1)	8.9 (8.4, 9.5)	Referent
- Taken medication for difficulties with emotions, concentration or behavior, including for attention-deficit/hyperactivity disorder †	57.2 (40.9, 72.1)	6.8 (5.1, 9.0)	14.7 (12.4, 17.2)	1.8 (1.5, 2.1)	7.1 (6.7, 7.6)	Referent
- Seen a specialist (other than mental health)	53.2 (36.5, 69.2)	2.4 (1.7, 3.5)	39.1 (36.2, 42.0)	1.8 (1.7, 2.0)	21.4 (20.6, 22.3)	Referent
Health Care Access						
- Has a usual source for sick care	94.7 (87.8, 97.8)	1.0 (1.0, 1.1)	92.0 (89.5, 93.9)	1.0 (1.0, 1.0)	92.9 (92.2, 93.5)	Referent
- Receives effective care coordination	43.7 (25.8, 63.3)	0.6 (0.4, 0.9)	62.8 (58.9, 66.4)	0.9 (0.9, 1.0)	69.3 (67.7, 70.7)	Referent
- Receives family centered care	56.3 (36.9, 74.0)	0.8 (0.6, 1.1)	63.5 (60.5, 66.5)	1.0 (1.0, 1.1)	64.5 (63.4, 65.6)	Referent
- Has a medical home	38.9 (24.8, 55.1)	0.7 (0.5, 1.0)	49.4 (46.4, 52.4)	0.9 (0.9, 1.0)	55.0 (53.9, 56.1)	Referent

† Abbreviations: CI = confidence interval; aPR = adjusted prevalence ratio;.

Table 4

Indicators of health, health care needs and health care access among children with Tourette Syndrome (current or ever) and no reported co-occurring mental disorders (Tourette Syndrome-only), children with Tourette Syndrome and at least one co-occurring mental disorder (Tourette Syndrome+Mental disorder) and children without Tourette Syndrome (never Tourette Syndrome).

	Tourette Syndrome-only (n = 61)		**Tourette Syndrome+Mental disorder† (n = 164)**		**No Tourette Syndrome (Never Tourette Syndrome) (n = 63,809)**	
	% (95% CI) †	**aPR† (95%CI)**	**% (95% CI)**	**aPR (95%CI)**	**% (95% CI)**	**aPR**
General Health Overall Health Fair or Poor	Not Reported	Not Reported	15.4 (8.5, 26.1)	4.6 (2.6, 8.4)	4.0 (3.5, 4.5)	Referent
Special Health Care Needs						
- Needs or uses medicine prescribed by a doctor	57.0 (37.1, 74.8)	2.4 (1.7, 3.4)	47.5 (31.6, 64.0)	2.0 (1.3, 2.9)	23.3 (22.5, 24.1)	Referent
- Needs or uses more medical care, mental health, or educational services	36.2 (19.1, 57.8)	2.5 (1.3, 4.6)	55.0 (36.8, 71.9)	4.0 (2.8, 5.7)	13.7 (13.0, 14.4)	Referent
- Limited or prevented in ability to do things	Not Reported*	Not Reported*	44.1 (27.7, 61.8)	6.1 (4.1, 9.2)	7.0 (6.5, 7.6)	Referent
- Needs or gets special therapy	Not Reported*	Not Reported*	35.3 (21.6, 51.9)	5.0 (3.4, 7.5)	7.4 (6.8, 7.9)	Referent
- Has an emotional, developmental or behavioral problem for which he/she needs counseling	Not Reported*	Not Reported*	72.8 (59.8, 82.8)	8.0 (6.7, 9.5)	9.1 (8.5, 9.6)	Referent
- Meets Criteria for children with special health care needs	55.9 (36.0, 74.0)	2.3 (1.6, 3.3)	63.9 (42.5, 80.9)	2.7 (1.9, 3.9)	22.7 (21.9, 23.6)	Referent
Health Care Needs						
- Received treatment or counseling from a mental health professional	7.4 (3.0, 17.2)**	0.5 (0.2, 1.4)**	52.1 (35.1, 68.6)	5.0 (3.5, 7.1)	9.8 (9.3, 10.4)	Referent
- Taken medication for difficulties with emotions, concentration or behavior, including for attention-deficit/hyperactivity disorder	Not Reported*	Not Reported*	64.8 (47.1, 79.1)	7.4 (5.7, 9.8)	7.8 (7.4, 8.3)	Referent
- Seen a specialist (other than mental health)	31.8 (18.2, 49.4)	1.1 (0.6, 2.0)**	45.2 (28.8, 62.7)	1.8 (1.2, 2.8)	23.2 (22.5, 24.1)	Referent
Health Care Access						
- Has a usual source for sick care	98.5 (94.0, 99.7)	1.0 (1.01, 1.08)	94.7 (88.7, 97.6)	1.0 (0.96, 1.06)	92.8 (92.2, 93.4)	Referent
- Receives effective care coordination	68.4 (46.0, 84.5)	1.0 (0.7, 1.4)	37.2 (23.1, 53.9)	0.5 (0.3, 0.8)	68.3 (66.9, 69.7)	Referent
- Receives family centered care	76.3 (51.3, 90.8)	1.1 (0.8, 1.5)	51.5 (34.2, 68.5)	0.7 (0.5, 1.1)	64.4 (63.3, 65.4)	Referent
- Has a medical home	61.1 (40.2, 78.6)	1.0 (0.7, 1.5)	31.1 (19.7, 45.3)	0.5 (0.3, 0.8)	54.4 (53.4, 55.4)	Referent

† Abbreviations: CI = confidence interval; aPR = adjusted prevalence ratio.

* Not reported because relative standard error > 55%.

** Relative standard error is >30% but less than 50% and should therefore the estimate should be interpreted with caution.